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ABSTRACT

The effects of broadening the definition of eligibility for services from the Washington State Division of Developmental Disabilities (DDD) are analyzed. Five different definitions are discussed. The existing definition includes: (1) "statutory conditions," which includes persons who are mentally retarded or have difficulty carrying out major life activities due to cerebral palsy, epilepsy, or autism; (2) "developmental delay under age 6," which includes young children who are limited in major life activities due to any condition; and (3) "continued developmental delay over age 6," which includes persons who are limited in major activities due to some condition occurring before adulthood. Proposed additions include: (4) "fetal alcohol syndrome among persons with IQ over 69," which would include individuals of all ages with this condition; and (5) "functional activity limitations occurring before age 21, caused by all other conditions" which would likely add a large number of clients. Limitations to the estimates are discussed. Individual sections of the report cover the context of these proposed changes, questions answered in the report, sources and methods for estimating effects on numbers of possible clients, possible client estimates, strengths and limitations of these estimates, and the likelihood that these possible clients will use DDD services An appendix includes an explanation of synthetic estimation methods. (Contains 44 references.) (CR)

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WHO IS ELIGIBLE FOR DDD SERVICES?

A 5-Year Analysis (July 1989-August 1994)

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Who is Eligible for DDD Services?

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EXECUTIVE SUMMARY

During the past decade, the Division of Developmental Disabilities (DDD) has broadened its service eligibility definitions. New changes to those definitions have been proposed. This paper analyzes both these actual and proposed changes in DDD eligibility, and presents estimates showing how each change affects the pool of possible DDD clients.

The definitions covered in this paper include three which are part of the 1995 DDD eligibility definition, and two which have been proposed for DDD eligibility in the past. They are:

A-Statutory Conditions Only (1995 Eligibility): Persons eligible under this definition are those who are mentally retarded (IQ under 70) or have difficulty carrying out major life activities due to cerebral palsy, epilepsy, or autism. These conditions are defined in Washington state statute and have traditionally been the major basis for DDD eligibility.

B-Developmental Delay Under Age 6 (1995 Eligibility): Persons added under this definition are those under age six who are limited in major life activities due to **any** condition other than the four statutory conditions from Definition A. These include chronic conditions such as sensory losses, paralysis; learning disabilities; and psychiatric disorders; disabling conditions such as juvenile arthritis and bronchitis, and long-term illnesses such as cancer and AIDS.

C-Continued Developmental Delay Over Age 6 (1995 Eligibility): Persons added under this definition are those over six who are limited in major life activities due to **some** condition occurring before adulthood other than the four statutory conditions. These conditions include only those which put a young person at risk of cognitive and developmental delays, such as severe sensory losses, neurological impairments, paralysis, and learning disabilities. Psychiatric disorders are excluded from this definition.

D: Fetal Alcohol Syndrome Among Persons with IQ Over 69 (Proposed): This proposal would add persons with Fetal Alcohol Syndrome who have IQs over 69 to DDD eligibility. All ages are included in this estimate, though persons over 25 with Fetal Alcohol Syndrome would be difficult to diagnose using current methods and hence would not be likely to impact the division immediately.

E: Functional Activity Limitations Occurring Before Age 21, Caused by All Other Conditions (Proposed): This definition adds all persons over age six with a limitation in major life activities which occurred before the age of 22 due to some condition not already covered in the previous definitions. This "functional" definition has been proposed at the Federal level. It would add many chronic and disease conditions, such as arthritis, psychiatric disorders, cancer and diabetes, to the more restricted list of conditions included in Definition C.

Figure 1 below illustrates the effect which each broadening of DDD eligibility would have had upon the possible client pool in 1993, had the definition been in effect for the entire lifetime of that 1993 population.

Figure 1: 1993 DDD Possible Client Estimates, Statewide

There were an estimated 5,327,233 Washington state residents in 1993. Figure 1 shows that the possible client pool under **Statutory Conditions (Definition A)** comprises a total of 128,403 persons -- 2.4 percent of the state population -- with the original statutory conditions of mental retardation, epilepsy, autism or cerebral palsy. This includes three groups of people:

- A count of 4,038 persons in DDD institutions and group housing, all of whom have substantial activity limitations.

- An estimate of 38,576 household residents **with major activity limitations** caused by any one or more of the four statutory conditions (mental retardation, epilepsy, cerebral palsy, autism).

- An estimate of 85,789 household residents who do **not** have a major activity limitation but do have an IQ below 70.

Figure 1 shows that there have been two major increases in the pool of possible DDD clients during the last decade. These estimated increases are based on national data on persons with functional limitation in major activities.

- **B - Developmental Delay Below Age Six**: Adding children under six with major activity limitations caused by any non-statutory conditions increased the possible client pool by about 18,013. This is a 14 percent increase over the "base" of the 128,403 persons with statutory conditions only.

- **C - Continued Developmental Delay Above Age Six:** Adding persons at or above the age of six with major activity limitations caused by "other" developmental but non-statutory conditions increases the pool yet again, by a much larger number (38,429).

Definitions A, B and C together make up the 1995 definition of DDD eligibility. Figure 1 also shows that two changes in DDD definitions which were proposed in 1994 have very different impacts upon the pool of possible clients.

- **D - Fetal Alcohol Syndrome and IQ Over 69**: Adding these persons to the statutory conditions would have a small effect on the possible client pool; adding only about 3,432 clients. Only about 36% of these persons would be under age 22, and diagnosable under present procedures. However, as years go by, more and more FAS cases will be diagnosed during childhood, and hence be eligible throughout their adult life, under this definition.

- **E - Functional Activity Limitation Caused Before Adulthood By Other Conditions:** Extending DDD eligibility to all other conditions which cause functional limitations adds a large number of people: 117,048 persons over age six with functional limitations in their major life activity caused by health conditions other than the four statutory conditions covered under Definition A, the continued developmental delaying conditions of Definition C, or the Fetal Alcohol Syndrome of Definition D.

The pool of possible clients discussed in this report is a group who are likely to be eligible for DDD services. However, "eligibility" does not translate directly into demand for services; it actually represents "need" for DDD services. The demand for DDD services will probably vary across this pool of possible clients.

Who among these possible clients is most likely to demand services of DDD?

- All of the non-retarded persons with Fetal Alcohol Syndrome who are under 21 (about 1,000 people in 1993) would be likely to ask DDD for services. This group would cumulate in the caseload; eventually being represented at all ages (about 3,000 persons total in 1993).

- About 50% of the families of the children in Definition B might demand services somewhere, though not necessarily from DDD. This represents about 9,000 persons in 1993.

- About 33% of the possible clients in Definition A (those who do have a major activity limitation) would be likely to demand DDD service. This is about 42,000 persons in 1993.

For persons under 21 in Definitions C and E, the extent of demand for DDD services among the possible clients is impossible to assess without additional information. Demand would vary with publicity, awareness of possible eligibility, service accessibility, and service design. Some use is already occurring in Definition C, so at least some potential demand definitely exists.

The following three groups are least likely to demand DDD services.

- Definition A contains a large number of people -- 67% of its extent, almost 86,000 persons in 1993 -- who are by law eligible for DDD services but are not likely to demand them.

- 50 to 60% of the parents of children in the Definition B estimates do not learn that their child is developmentally delayed until the child is in school. They are unlikely to demand services earlier (though widespread developmental screening might bring them in).

- Definitions C and E contain many adult persons who have lived their entire lives without DDD service entitlements. If these persons have major activity limitations, they are probably entitled to long-term care services from the Aging and Adult Services Division. Therefore, most of them are unlikely to demand services from DDD as long as the services available do not change, though a few might present themselves as a result of life crises.

INTRODUCTION AND CONTEXT

Over the past ten years, the Washington State Division of Developmental Disabilities (DDD) has been moving from an institutional care model to a community care model. This change has been well-documented in DDD plans and documents, and is consistent with national policy towards persons with developmental disabilities.

During the same decade, DDD service eligibility definitions have changed several times, and new changes are still under discussion. This paper presents estimates of the cumulative effect of these change definitions on the pool of "possible" DDD clients -- those persons who are estimated as "likely to be eligible" for DDD service -- had the changes been in place for the entire lifetime of all possible clients.

In the early 1980's, a typical DDD client was someone who was "substantially handicapped" in carrying out his or her daily activities, due to conditions defined in statute -- mental retardation, cerebral palsy, epilepsy, autism or other similar neurological conditions. These four eligibility conditions, and the levels which entitled clients to services, were defined in statute; in this paper, they are called "Statutory Conditions".

When conferred by professional examination, DDD eligibility was permanent. It was assumed by both the Legislature and the general public that these conditions and the substantial handicaps they caused would not change over the person's lifetime. Once eligibility was established, then, DDD staff concentrated upon helping clients and families deal with their permanently handicapping conditions.

In 1986, DDD began to provide some services to young children -- originally from birth to three years of age, later from birth to six -- who had "developmental delays". For some clients, those delays were caused by statutory conditions; for others, the delays were caused by different sorts of conditions. The Birth to Six program concentrated on finding developmentally delayed children under six and getting them to services quickly.

However, unlike statutory eligibility, a status of "Developmental Delay" under age six did not automatically entitle clients to permanent DDD services. On the contrary, it was hoped that serving the children early would lessen the permanent handicap and the need for later service by providing enrichment and stimulation while the brain was developing. Therefore, children who entered with developmental delays were to be reviewed at age three and age six, to see if they still needed DDD services. By age six, it was assumed that either this temporary eligibility would be converted into a permanent eligibility through a statutory condition diagnosis, or the child would leave the DDD service system.

In 1989, DDD began to use another form of "temporary" eligibility certification, this time for Continued Developmental Delay in persons over the age of six. This evaluation was intended to meet the statutory language which said that a person with a "substantial handicap" who "needed services similar those required for mental retardation" was eligible for DDD services, even if the existing statutory health conditions were not met. DDD has implemented that condition as follows: if persons over six were in special education classes, and their placement was not caused solely by psychiatric, behavioral, "orthopedic" or "sensory" handicaps, then they could be evaluated for the presence of continued substantial developmental delay. Again, such eligibility was not presumed permanent. These clients were to be evaluated every two years to see if their delay continued.

During the 1994 legislative session, two additional changes in the caseload were discussed. Both represent expansions of the existing permanent eligibilities.

The first proposed change was the addition of Fetal Alcohol Syndrome (FAS) to the list of conditions which lead to permanent DDD eligibility. This proposal was based upon clinical research which showed that even the 42% of FAS cases who were not mentally retarded had characteristic severe cognitive difficulties which did not improve with age, and which affected all spheres of learning. These learning difficulties meant that FAS cases had great difficulty leading an adult life, and needed continual life support, case management and supervision if they were to live in the community.

The second proposed change is typically called a Functional Definition: it would extend permanent DDD eligibility to all persons with substantial handicaps originating before adulthood, if those handicaps are caused by permanent physical or mental conditions, regardless of the type of condition. This is the broadest change possible: it essentially extends the Birth-to-Six eligibility definition to all conditions occurring before age 22.

QUESTIONS ANSWERED IN THIS REPORT

This paper explores these actual and proposed changes in DDD eligibility, and asks how each affects the pool of **possible DDD clients** -- the "potential market" for DDD services. It discusses both the estimated number of additional clients under each definition and the types of new conditions which each new definition would cover.

This paper discusses the separate effect each definition would have had upon the estimated pool of possible clients, had those definitions been in place for the entire lifetime of the population during each year. Therefore, any "bow wave" which DDD might experience in the future (because of extending services to previously ineligible children and their families) is included in these estimates.

SOURCES AND METHODS

Since possible clients cannot be counted directly without expensive surveys, this paper relies on synthetic estimation methods. Synthetic estimates take subgroup rates of particular conditions from national or regional surveys and apply them to similar subgroups in smaller areas. For example, a national survey may find that 2.2 percent of White non-Hispanic persons aged 11 through 21 have IQ scores below 70. In King County, during 1990, there were 154,716 White non-Hispanic people aged 11 through 21. Multiplying 2.2 percent times 154,716 gives an estimate of the White non-Hispanic 11 to 21 year olds who are mentally retarded -- 4,332.

Synthetic estimates of possible clients, of course, are not actual counts. They often do not come from studies designed to provide exactly the needed information. In this report, some of the persons described under each definition might **not** be found eligible, if they requested service. However, these estimates come as close as possible to true service eligibilities, given the information provided from existing sources.

The synthetic estimates of possible clients in this paper are drawn from four types of sources:

1. Research literature on Fetal Alcohol Syndrome, on mortality rates for persons with disabling conditions, and on the rates of persons below IQ 69 who are living successfully in the community with no special assistance.

2. Population data from the U.S. Census (1990) and updates maintained by the DSHS Office of Research and Data Analysis for 1991 through 1993.

3. Data on clients in group housing from the FY92 Needs Assessment Data Base, maintained by the DSHS Office of Research and Data Analysis.

4. Interview data on limitations of major life activity caused by chronic and acute health conditions from the National Health Interview Survey. This annual survey of U.S. households, conducted by the National Center for Health Statistics, is large, comprehensive, and has excellent survey cooperation (in 1991, only 4.4% of the households contacted refused to participate). The face-to-face survey asks a series of questions about functional limitations and their main and secondary causes. A single adult respondent in each survey household is questioned about each member of the household.

Details on the estimating methods, their strengths, and their limitations are presented in Appendix A. The concepts and measurement methods for each estimation are summarized briefly in Table 1 below.

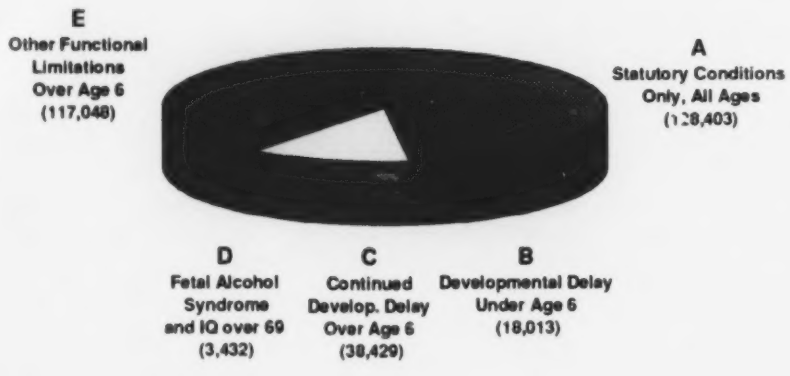
Table 1: Conceptual and Operational Definitions of DDD Possible Clients

Conceptual	Operational
A **Statutory Conditions Only** (Mental Retardation, Cerebral Palsy, Autism or Epilepsy)	• All Washington State residents except those in DDD residential facilities are used as a base, divided into age-by-race/ethnic subgroups. • Those population subgroups are multiplied by matching subgroup prevalence rates from the NHIS. Those rates show the percentage of persons who are limited or prevented from carrying out their major life activity AND have at least one of the following four conditions as the main cause of that activity limitation: mental retardation, cerebral palsy, autism or epilepsy. • Based upon research literature, an estimate of mildly retarded community residents who are **not** functionally limited is added. • A count of DDD residential clients (who would not be captured in the NHIS household rate) is added.
B **Developmental Delay Under Age Six:** Adds all new causes of major activity limits for children under 6.	• Washington State residents under age six who are not in DDD residential facilities are used as a base, divided into age by race/ethnicity subgroups. • Those subgroups are multiplied by matching subgroup prevalence rates from the NHIS. Those rates show the percentage of persons who are limited in or prevented from carrying out their major life activity (which is play and school for this age group), due to any condition EXCEPT mental retardation, cerebral palsy, autism or epilepsy.
C **Continued Developmental Delay Over Age Six:** Adds some new causes of developmental delay for persons over age six.	• Washington State residents over age six who are not in DDD residential facilities are used as a base, divided into age-by-race/ethnic subgroups. • Persons under 21 by subgroup are multiplied by matching subgroup prevalence rates from the NHIS. These rates show the percentage of persons limited or prevented from carrying out their major life activity) **mainly due to** any of the following conditions: severe vision or hearing impairments, Hyperkinetic syndromes, speech defects, specific learning delays, paralysis, loss of legs, loss of arms, loss of organs, brain cancer, spinal cancer, immune system disorders, organic mental disorders, central nervous system degenerative diseases, congenital abnormalities of the brain and spinal column. • The estimated case rate at age 21 is used as a base for persons over 21, but is reduced in five year age groups by mortality rates which are higher than the general population mortality rate.
D **Fetal Alcohol Syndrome, IQ over 69:** Adds 42% of FAS cases	• For each year, Washington State live infants are used as a base, multiplied by a rate of FAS cases per thousand births. • The resulting cases are reduced in five year age-groups by mortality rates which are higher than the general population mortality rate. • The total estimated cases are reduced by 52%, which is the rate of mental retardation among FAS cases.
E **Functional Activity Limits Over Age Six:** Adds all other causes of major activity limits to persons over age six.	• Washington State residents who are not in DDD residential facilities are divided into age by race/ethnic subgroups. • Those subgroups are multiplied by matching subgroup prevalence rates from the NHIS. These rates show the percentage of persons limited or prevented from carrying out their major life activity due to **any** condition acquired before age 22. • The estimated case rate at age 21 is used as a base for persons over 21, but is reduced in five year age groups by mortality rates which are higher than the general population mortality rate. • The final total is reduced by subtracting all the previous definitions

POSSIBLE CLIENT ESTIMATES

Figure 1 below illustrates the effect of each broadening of DDD eligibility upon the possible client pool. This figure, and the tables which follow, are based on the assumption that each change has been in effect, and influencing each year's DDD possible client pool, for ninety years. Thus these estimates include the full effect of the definitions across all ages (unlike the current DDD caseload which shows the effects of Definitions B and C only in clients under age nine).

Figure 1: 1993 DDD Possible Client Estimates, Statewide



There were an estimated 5,32,233 persons in Washington State in 1993. Figure 1 shows that using **Statutory Conditions Only** (Definition A), an estimated 128,403 of those persons (2.4 percent of the population) meet the statutory conditions of mental retardation, epilepsy, autism or cerebral palsy. This definition includes three groups of people:

- An FY92 count of 4,038 persons in DDD institutions and group housing, all of whom have major activity limitations.
- An estimate of 38,576 persons in households with a major activity limitation caused by any one of the four statutory conditions (mental retardation, epilepsy, cerebral palsy, autism).
- An estimate of 85,789 persons in households who do **not** have a major activity limitation but are mentally retarded (have an IQ below 70).

Figure 1 shows that there have been two major increases in the pool of possible DDD clients during the last decade. Both of these increases involve only persons with major activity limitations:

- **B - Developmental Delay Below Age Six:** Adding children under six with major activity limitations caused by non-statutory conditions has increased the possible client pool by about 18,013. This is a 14 percent increase over the "base" of the 128,403 persons with statutory conditions only.

- **C - Continued Developmental Delay After Age Six**: Adding persons over the age of six with major activity limitations caused by "other" developmental but non-statutory conditions increases the pool yet again, by a much larger number (38,429).

Figure 1 also shows that two changes in DDD definitions which were proposed in 1994 have very different impacts upon the pool of possible clients.

- **D - Fetal Alcohol Syndrome Among Persons with IQ Over 69**: Adding non-retarded persons with Fetal Alcohol Syndrome to the statutory conditions would have a small effect on the possible client pool; adding only about 3,432 clients. Any person with diagnosed Fetal Alcohol Syndrome is presumed eligible; however, such diagnoses are likely at present only in persons under age 22.

- **E - Functional Activity Limits Occurring Before Age 21**: Adding all other conditions which occur before 21 and cause functional activity limits would have a drastic effect on the possible client pool. This change would add 117,048 persons over age six with functional limitations in their major life activity which are caused by health conditions not included in any of the previous definitions.

Each definition adds new types of conditions to the DDD "condition pool", as well as new estimated possible clients. What new conditions are added?

Definition C adds the following "main causes" of activity limitation in persons over six to retardation, cerebral palsy, autism and epilepsy.

Table 2: New Conditions Added Under Definition C

Severe sensory losses in both eyes or ears	AIDS and HIV, other immune systems disorders
Speech defects, with or without cleft palate	Slow viruses of the central nervous system
Specific learning disabilities and developmental delays	Spinabifida & other severe deformities of the spine or back
Hyperkinetic syndrome	Brain and spinal cancers
Absence or loss of 2 arms, 2 legs, or major organs	Hereditary and degenerative diseases of the central nervous system
Paralysis, excluding cerebral palsy	Organically caused mental disorders

Definitions E (for everyone above age 6) and B (for ages 6 and under) bring in the following new "main cause conditions" listed below, in addition to the statutory conditions and those added by Definition C above. These are the most frequent conditions, but there are many others which occur less frequently.

Table 3: New Conditions Added with Definitions E and B

Arthritis, other joint diseases, disc and joint disorders	Sinusitis, tonsillitis, other chronic ear, nose and throat problems
Psychiatric Disorders	Hypertension
Asthma, Bronchitis, Allergies	Various liver and kidney diseases
Structural deformities and impairments (mostly back and legs)	Sensory losses in one ear or eye, or minor eye and ear disorders
Sickle cell	Ulcers and other gastric problems
Metabolic disorders	Blood clotting problems
Diabetes	Glandular disorders
Cancer	Heart disease, palpitations
Partial paralysis	Skin infections and conditions
Migraine, other headaches	Muscular dystrophy

Table 4 below shows possible client estimates by age group. Because the estimating process requires an additional step in persons over 21 (estimating excess mortality caused by the added conditions), Definitions C, D and E are somewhat more precise for the under-21 age group than for the older group.

Four base year populations are modeled in Table 4: 1990 through 1993. Each year represents the entire number of possible clients for that year. The year to year changes show the effect of the growth of the state population on the estimates of possible clients. Percentages are included for 1993.

Table 5 below shows how the 1993 possible client estimates under each definition are distributed by region. The regional percentages, if calculated, would differ slightly from one another and from the statewide averages because regional populations differ in age and ethnic composition.

Table 4 STATEWIDE POSSIBLE CLIENT ESTIMATES BY AGE, 1990 TO 1993

	All five DDD eligibility definitions begin with people with severe functional limits in major life activities, such as communication, play, school and work. The conditions causing these limitations must originate in childhood. An estimate of persons who have IQs below 70 but do not report severe functional limitations in major life activities is then added to Definition A. This group is 67% of Definition A possible clients.											
	CURRENT DDD POSSIBLE CLIENTS								**PROPOSED ADDITIONAL POSSIBLE CLIENTS**			
	A		**B**		**C**		**A+B+C**		**D**		**E**	
	Statutory Conditions Only (Mental Retardation, Cerebral Palsy, Autism or Epilepsy)		**Develop-mental Delay Under Age 6:** Adds all new causes of major activity limits for children under age six		**Continued develop-mental Delay Over Age 6:** Adds some new causes of develop-mental delay for persons over six		**Total Possible Clients Under Current Eligibility Definition**		**Fetal Alcohol Syndrome Among Persons with IQ Over 69:** Adds Non-Retarded Persons with FAS		**Functional Limitations all Other Causes:** Adds all other causes of major activity limits to persons over age six	
1993												
Under 6 Years	*3.5%*	16,832	*3.7%*	18,013			*7.2%*	34,845	*0.1%*	370		
Aged 6-21	3.8%	44,391			*1.2%*	13,610	*4.9%*	58,001	*0.1%*	874	*1.9%*	25,796
Over 21 years	*1.8%*	67,180			*0.7%*	24,819	*2.5%*	91,999	*0.1%*	2,188	*2.5%*	91,252
TOTAL	*2.4%*	**128,403**	*0.3%*	**18,013**	*0.7%*	**38,429**	***3.5%***	**184,845**	*0.1%*	**3,432**	*2.2%*	**117,048**
1992												
Under 6 Years		16,482		17,623				34,105		362		
Aged 6-21		43,158				13,267		56,425		849		25,163
Over 21 years		65,525				24,314		89,839		2,138		89,369
TOTAL		**125,165**		**17,623**		**37,581**		**180,369**		**3,349**		**114,532**
1991												
Under 6 Years		16,047		17,141				33,188		352		
Aged 6-21		42,182				12,966		55,148		829		24,469
Over 21 years		65,135				23,849		88,984		2,093		87,576
TOTAL		**123,364**		**17,141**		**36,815**		**177,320**		**3,274**		**112,045**
1990												
Under 6 Years		15,333		16,347				31,680		336		
Aged 6-21		41,385				12,699		54,084		812		23,956
Over 21 years		60,692				23,259		83,951		1,990		85,592
TOTAL		**117,410**		**16,347**		**35,958**		**169,715**		**3,138**		**109,548**

Source: ORDA Estimates.
Percents are of the 1993 population in the appropriate age group.

Table 5: REGIONAL POSSIBLE CLIENT ESTIMATES, 1993

	All five DDD eligibility definitions begin with people with severe functional limits in major life activities, such as communication, play, school and work. The conditions causing these limitations must originate in childhood. An estimate of persons who have IQs below 70 but do not report severe functional limitations in major life activities is then added to Definition A. This group is 67% of Definition A possible clients.					
	CURRENT DDD POSSIBLE CLIENTS				**PROPOSED ADDITIONAL POSSIBLE CLIENTS**	
	A	**B**	**C**	**A+B+C**	**D**	**E**
	Statutory Conditions Only (Mental Retardation, Cerebral Palsy, Autism or Epilepsy)	**Develop-mental Delay Under Age 6:** Adds all new causes of major activity limits for children under age six	**Continued develop-mental Delay Over Age 6:** Adds some new causes of develop-mental delay for persons over six	**Total Possible Clients Under Current Eligibility Definition**	**Fetal Alcohol Syndrome Among Persons with IQ Over 69:** Adds Non-Retarded Persons with FAS	**Functional Limitations all Other Causes:** Adds all other causes of major activity limits to persons over age six
Region 1	17,089	2,378	5,091	24,558	445	15,244
Region 2	11,654	1,798	3,326	16,778	307	10,401
Region 3	20,043	2,998	6,165	29,206	535	18,271
Region 4	37,137	4,834	11,233	53,194	1,032	35,363
Region 5	21,346	3,155	6,219	30,720	559	18,863
Region 6	21,135	2,850	6,404	30,389	553	18,908
TOTAL	**128,403**	**18,013**	**38,428**	**184,844**	**3,431**	**117,048**

STRENGTHS AND LIMITATIONS OF THESE ESTIMATIONS

Many of these estimates draw upon the National Health Interview Survey (NHIS). In the NHIS, one member of a household is interviewed about the health conditions and functional limitations of all household members. This survey is large and well-administered, with a cooperation rate of over 95% of all eligible households. The design is powerful and it permits cross-classification of many health conditions with several definitions of functional limitation.

Using the NHIS for many of the definitions in this paper adds strength to the estimates, primarily because it makes possible a common definition of "functional limitation" or "substantial handicap" for all eligibility conditions. That definition is, a person who **is limited in or prevented from carrying out his or her major life activity**. The major life activity is as follows: play for preschool children (birth through five), school for school-age children (5 through 18), work/housework for adults 18 through 65, and personal care for adults over 65.

However, there are several ways in which the NHIS will produce different prevalence rates than would a "gold standard" survey, such as a random sample of the population which is thoroughly screened and professionally assessed for the presence of disabling conditions and functional limitations. Systematic underestimates of the prevalence of health conditions can occur within the NHIS, particularly if those conditions are stigmatizing, are not known immediately at birth by physical signs, and have little immediate impact upon functionality. Population subgroups whose members are less likely to seek help may also be less likely to discuss their health conditions with survey researchers. And, of course, people who are not living in households are not included.

Overestimates of functional limitations may also occur when using the NHIS if the DDD definition of functional limitation is much "stricter" than any NHIS definition used in the NHIS. If the NHIS is to be consistently used to estimate the prevalence of functional disability which DDD is actually measuring with some other process, it might be wise to plan a small comparison study which would "calibrate" the two definitions.

This report corrected in various ways for the problems presented by the National Health Interview Survey. The estimates and the corrections are addressed below for each definition.

Definition A: In the statutory authority for the Division of Developmental Disabilities, one condition requires no additional "functional limitation": mental retardation. Anyone with an IQ under 70 is eligible for DDD services, even if they are successfully carrying out their life in the community. However, community studies reported in the research literature show that well over half of the persons with IQ below 70 are successfully living in the community with no special assistance. Most of these people have IQs between 55 and 69. They

often have had trouble in high school and may have needed to repeat a grade, but they learn a trade and are employed, have friends and families, and look like everyone else -- just a little slower. Such people do not define themselves as mentally retarded or as having activity limitations. Hence they are unlikely to be included in this NHIS-based estimate.

For this report, community surveys were used to ascertain the overall rate of persons with IQs under 70 -- about 21 per thousand persons (Granat and Granat 1973; Zigler and Hodapp 1986). Estimates of the number of persons whose major activity limitations were mainly caused by cerebral palsy, autism or epilepsy were drawn from the NHIS and added.

Since ethnic and age characteristics for this mentally retarded but functional group were not clearly established in the research literature, the population characteristics from the (known) NHIS rates for persons who have major activity limitations due to mental retardation, cerebral palsy, autism or epilepsy were applied to the entire group.

All DDD clients living in group quarters and institutions (and hence not part of a household or community survey) are included in these estimates. The actual counts come from the 1992 Needs Assessment Data Base maintained by the DSHS Office of Research and Data Analysis. If Washington State is more likely than the nation as a whole to house developmentally delayed persons in their own households rather than in group quarters and institutions, this method will produce a slight underestimate of possible clients.

Definition B: For Definition B, numbers of Washington state children under age six were multipled by rates from the NHIS of persons with limitations in major life activity **not** caused by the four statutory conditions. The rates used were drawn from NHIS reports for children six through ten rather than children under six. This is to correct for under-reporting of developmental delays in preschool children, which result from the time it takes to notice a delay, screen and diagnose a child. Until that process is complete, the parent will not know (though they may suspect) that the child is delayed, and hence will not report a limitation to a survey interviewer.

Definition C: This is a somewhat restricted version of extended eligibility for persons over age five. This definition includes persons with "substantial handicaps" who "need services similar to those required for mental retardation." The rates include all persons identified in the NHIS whose major activity limitation originated between six to 21 years of age and who had one of the conditions listed in Table 6 below as a main cause of that limitation. These persons are then "aged" using a Standardized Mortality Ratio (SMR) drawn from retarded persons living in the community, which adjusts for expected higher-than-general-population mortality rates among this group.

Table 6: Conditions Included in Definition C

Severe sensory losses in both eyes or ears	AIDS and HIV, other immune systems disorders
Speech defects, with or without cleft palate	Slow viruses of the central nervous system
Specific learning disabilities and developmental delays	Spinabifida & other severe deformities of the spine or back
Hyperkinetic syndrome	Brain and spinal cancers
Absence or loss of 2 arms, 2 legs, or major organs	Hereditary and degenerative diseases of the central nervous system
Paralysis, excluding cerebral palsy	Organically caused mental disorders

Whether this estimate is an accurate picture of the possible clients depends upon the answers to the following three questions.

- Do the conditions above actually represent most of the situations where "services similar to those required for mental retardation" would be useful? Are there other conditions which should have been included?

- If a person is "limited or unable to perform a major life activity" will they also score in the bottom quartile of the ICAP measure which DDD is presently using for their functional evaluations? This question could be addressed empirically, but no published research has compared these measures.

- Overall, do the group of people with these conditions have similar survival rates to mentally retarded persons living in the community? If not, are their survival rates lower (in which case this number is an overestimate) or higher (then this number is an underestimate)?

Even though the list of added conditions in Definition C is relatively limited, the effect upon the possible client pool is large. This may be an overestimate, because everyone between ages 6 and 21 who develops those conditions and is limited in his or her major life activity is included. Some of these conditions (for example, brain or spinal cancer) are curable: a person with brain cancer might need DDD services for a time, and then need them no longer.

Definition D: This definition includes only those cases of Fetal Alcohol Syndrome where the person has an IQ over 69. FAS is not recorded in the NHIS as diagnosis, so the research literature was used to arrive at a rate of FAS cases per 1000 births, and an age-specific death rate based upon the SMR for mentally retarded persons in the community.

Some children with Fetal Alcohol Syndrome may have been reported in the NHIS sample as having "learning disabilities". If so, the effect of FAS is even smaller than predicted here, because those children have already been counted as "developmentally delayed over age six" (Definition C).

Definition E: This definition is included because it was discussed during the 1994 legislative session, and because it represents a proposed federal definition of developmental disability. For some of the conditions which occur under this definition, services such as case management, personal care and group housing are already administered by two other DSHS units: the Mental Health Division, and the Aging and Adult Services Administration. Were such a "functional definition" of DDD eligibility to be discussed again in this state, it might be useful to exclude some groups of conditions.

WILL THESE POSSIBLE CLIENTS USE DDD SERVICES?

The possible client pool discussed in this report is essentially a group of people who are likely to be eligible for services from DDD. However, eligibility does not translate directly into demand. How likely is it that all these possible clients would ever perceive themselves as having a problem which might be helped by DDD services? The answer differs for each definition.

What possible clients are likely to demand services of DDD?

- All of the non-retarded persons with Fetal Alcohol Syndrome who are under 21 (about 1,000 people in 1993). The well-publicized cognitive and behavioral difficulties faced by persons with FAS makes it likely that DDD services would appeal to their families as they try to prepare their children for adult life. This group would cumulate in the caseload; eventually being represented at all ages to reach their maximum of about 3,000 persons.

- About 50% of the families of the children in Definition B might demand services somewhere, though not necessarily from DDD. This represents about 9,000 persons in 1993.

About 33% of the possible clients in Definition A (those who do have a major activity limitation) would be likely to demand DDD service. This is about 42,000 persons in 1993.

Which possible clients are least likely to demand DDD services?

- Definition A contains a large number of people -- 67% of its extent, almost 86,000 persons in 1993 -- who are by law eligible for DDD services but are not likely to demand them. This same proportion has been identified in several community surveys as retarded persons who do not use community or state services (Granat and Granat 1973, 1978, Reschly and Jipson 1976, Birch et al 1970).

- 50 to 60% of the parents of children in the Definition B estimates do not learn that their child is developmentally delayed until the child is in school. They

are unlikely to demand services earlier (though widespread developmental screening might bring them in).

- Definitions C and E contain many adult persons who have lived their entire lives without DDD service entitlements. If these persons have major activity limitations, they are probably entitled to long-term care services from the Aging and Adult Services Division. Therefore, they are unlikely to demand services from DDD.

- Persons in Definition E are self-defined as having a problem, so they may demand services. However, it seems unlikely that most of them would find DDD services as presently constituted helpful for solving those problems. If they were added to the eligibility pool, perhaps DDD would need to change its service mix and become the long-term care division for persons disabled during their youth, rather than the agency dealing with the specialized set of disabilities which have strong developmental impacts.

For some groups of possible clients, the proportion of "demand" among the possible clients is impossible to assess without additional information. Demand would probably vary with publicity, awareness of possible eligibility, DDD service design, and crisis points in the life of the persons needing services.

- Definitions C and E contain only persons who are defined by themselves or their families as having major activity limitations. Demand is particularly likely among persons under the age of 21, who would not be eligible for personal care or family support services from any other state agency. If these persons or their families become aware that (1) DDD services exist, (2) they may be entitled to use them, and (3) those services seem desireable, increased demand is likely to result. This knowledge would probably be conveyed through professionals such as teachers, school counselors, doctors, medical social workers and nurses.

- Most adults in Definitions C and E would be unlikely to demand services. However, there are crisis points (such as the death of parents who have been providing support) which could send such persons searching for services.

APPENDIX A: SYNTHETIC ESTIMATION METHODS

INTRODUCTION TO GENERAL VALIDITY ISSUES

Synthetic estimations take subgroup rates (such as the prevalence of mental retardation among White non-Hispanic men aged 15 through 24) from national or regional surveys, and apply them to similar subgroups in small areas. Overall estimates for the small areas may then be constructed by appropriately combining the subgroup estimates. When precise small-area information is unavailable, synthetic estimates can be very useful to policy-makers in answering a variety of "what-if" questions.

However, there are several issues which need to be considered in deciding whether the assumptions underlying the synthetic estimates reflect reality in a manner appropriate to the questions at hand (in other words, which affect the "validity" of the estimates). Different strategies are needed to reduce the various threats to validity which may occur. These threats, and their solutions, need to be carefully considered and balanced in synthetic estimation designs, because in some situations, efforts to reduce the potential impact of one threat to validity may increase the impact of another.

The general issues and strategies are described briefly below, and will be referenced in the method discussions which follow.

Issue	Strategy
Appropriateness of Indicators	The rate which is measured in the large area survey should be conceptually and operationally close to the desired characteristic or rate in the small area.
Relevance of Subgrouping Variables	The large area survey should show a strong relationship between the rate in question and subgroup membership (age, gender, race/ethnicity). In other words, the rates should vary across subgroups; otherwise it makes no sense to use them.
Comparability of Subgroup Populations	The nature of the large area subgroup populations should be similar to the nature of the small area subgroups.
Stability of Large-Area Estimates	The large area survey should be large enough to provide valid rates for all subgroups.
Uncontrolled Differences between Large and Small Area	If the small area differs from the larger one in some way which is not accounted for by the subgrouping variables used in the estimation procedures, the synthetic estimates will not reflect them. It may be possible to include some area-specific adjustments, if even one subgroup can be directly measured on relevant characteristics across both the large and the small areas.
Comparing Several Synthetic Estimates	If estimates for several different populations are being compared, differences in estimation method should be minimized.

GENERAL SOURCES AND DEFINITIONS

Several of these estimates use two sources of data: the National Health Interview Survey, and mortality rates drawn from national literature and compared to the overall U.S. mortality rate. A description of each source and the relevant validity issues follows.

The National Health Interview Survey (NHIS)

This annual survey of U.S. households, conducted by the National Center for Health Statistics, is large, comprehensive, and has excellent survey cooperation (in 1991, only 4.4% of the households contacted refused to participate). The face-to-face survey asks a series of questions about functional limitations and their main and secondary causes. A single adult respondent in each survey household is questioned about each member of the household.

In possible client estimates for Definitions A, B, C and E, the following functional limitation definition from the NHIS was used as an operational measure of "substantial handicap:" persons who have a chronic or long-term health condition which limits or prevents them from carrying out their major life activity. The "major life activity" varies by age; it is play for children under five, school for five through 17 year olds, employment or household work for persons 18 through 64, and personal care for persons over 65.

Conceptually, this functional definition fits the legislation relatively well. It is likely to lead to some overestimates of DDD eligibility, since people could be modestly "limited" in their ability to carry out their major life activity. Hence it identifies a pool of disabled persons, most of whom will be substantially handicapped by their disability.

For Definition B and E, the NHIS weighted survey data from 1988, 1989, 1990 and 1991 were combined to arrive at larger subgroup estimates. For definitions A and C, 1990 was not used, because the weighting system used on the "condition" file for that CD-ROM was different than weighting systems used in prior and subsequent years, making it impossible to combine the years. For Definition C, another year -- 1988 -- was removed, because the program which retrieved subsets from the CD-ROM on which the data is stored seemingly could not handle complex selections.

The NHIS defines race and Hispanic ethnicity with separate questions. For these analyses, the two categories were combined: Hispanics were removed from the race categories and grouped together as "Hispanic, all races."

The NHIS subgroups, because they are based on a national sample, differ in some significant ways from Washington State's population. Washington State is

more rural than the nation as a whole. Also, NHIS "Hispanics" are of mixed national origin (Mexican, Cuban and Puerto Rican) while Washington's Hispanics are primarily of Mexican descent. And, of course, while American Indians in Washington come from all tribes and from Alaska as well, our American Indian population is more heavily weighted towards local Indian nations.

The impact of these subgroup differences are probably relatively minimal. More to the point, they affect all the eligibility definitions which use the NHIS equally, so they do not change the relative size of the various definitions which are used.

Table A-1 below shows the age by race/ethnicity rates for persons having a limitation in major life activity. Whenever possible, these age/race categories (with different rates, of course) were used as a basis for definitions.

It is clear from these tables that race/ethnicity has some "face validity": it does affect the likelihood that a child will be defined by their parent as having a limitation in their major life activity. These ethnic differences show up again in DDD client data, so it seems possible that the differences in parental reporting do reflect differences in the underlying prevalence of various conditions. At least they reflect the likelihood that persons in these ethnic groups will request services for a disability.

Table A-1: Percent of Persons with Limitations in Major Life Activity

	Birth to Six	**Six to Ten**	**Eleven to 21**
White non-Hispanics	1.92	5.04	4.72
African-American non-Hispanics	2.68	5.19	5.08
American Indian non-Hispanics	1.51	7.73	6.77
Asian-American non-Hispanics	0.77	2.06	1.74
Other non-Hispanics	1.23	4.50	3.76
Hispanics of all races	1.93	4.81	4.09
TOTAL	***1.98***	***4.97***	***4.62***

SOURCE: National Health Interview Survey, 1988 through 1991.

In this database, however, a child's age probably misstates the true disability prevalence. Overall, children ages birth through five are shown as having about a 2 percent disability rate, while children ages six through ten are shown as having a 5 percent disability rate. This difference probably reflects differences in the parent's knowledge that the child has a disabling condition, since many of the problems involved are more likely to surface once the child is in school. Therefore, for all the analyses in this report, rates in the six to ten year old age group are substituted for rates in the birth to five year old age group.

The most restrictive definitions (A and C) involved specific condition lists. Also, for both of these definitions less than four years of NHIS data were involved.

Therefore, for those two definitions, the two smallest ethnic groups (American Indians and Asians) were combined with "others" and given a single rate.

This combined approach works reasonably well at the state level, because this state has approximately equal numbers of Asians and American Indians. However, it is not desirable at the local level for two reasons: Asians and American Indians are concentrated in different counties, and the data for the other definitions suggests that American Indian rates will be unusually high and Asian rates unusually low (relative to White non-Hispanics). If these distinctions persist at the policy level, and as future years of NHIS data become available, these estimates should be reanalyzed with a full ethnic breakdown.

Estimated Mortality Rates for Disabled Persons Over Age 21

The NHIS does not define when a household member who was disabled became disabled. For such disabilities as "mental retardation" or "cerebral palsy", this was not an issue, because the conditions themselves were life-long and established during childhood. Therefore, for every age after six, the actual age-group prevalence could be established.

However, other conditions described in this paper occur more frequently after age 21 than before. For these conditions, to determine the number of persons over 21 who had functional disabilities stemming from conditions acquired before age 21, the following steps were necessary:

1. establish a disability rate based on persons who were 21 years old.

2. define age-specific death rates for those persons.

3. compare those death rates to the general population mortality rate, and establish a relationship between general population mortality and the condition-specific mortality.

4. apply the statistical relationship to the disability rate.

The most difficult part of this process is Step 2, the establishment of age-specific death rates for persons with those conditions. The standard methodology for attributing deaths to conditions reports the actual condition which led to the person's death -- the "underlying cause of death." However, the sorts of disabilities DDD is concerned with are seldom the direct, underlying cause of death. Persons with mental retardation die younger than the general population, but the "underlying cause of death" is seldom coded as "Retardation." Rather it is pneumonia, or cancer, or heart failure.

Overcoming this problem required a search of the research literature to find large studies which began with groups of patients and then established age-

specific death rates for those patients. To establish death rates related to the condition rather than institutionalization, the studies needed to include persons in the community, and they needed to extend over a long time period.

The most frequent conditions causing major activity limitation in non-retarded persons aged 19 to 22 are mental illness (24.6%), asthma and other respiratory disorders (10%), rheumatoid arthritis (24.6%) and various types and levels of orthopedic impairments. The research literature was searched for clear rates of elevated mortality associated with these conditions, and for clear indications of elevated mortality for persons with Fetal Alcohol Syndrome.

Psychiatric disorders have long been associated with elevated mortality rates (for example, see Malzberg 1932), but the actual rates and their causes have varied as mentally ill persons moved from hospitals to community settings. Among hospitalized patients, both "natural" deaths (from infections and diseases) and "unnatural" deaths (from suicides or accidents) are elevated. In community settings, most excess mortality is caused by unnatural deaths (Black et al 1985b, Martin et al 1985, Allgulander 1994).

A 1985 study by Black, Warrack and Winokur (1985a) searched death records for all 5,412 patients admitted to the University of Iowa Psychiatric Hospital during a ten-year period. They found that the overall ratio of observed to expected deaths (the Standardized Mortality Ratio, or SMR) was 1.7, indicating a 70% increase in death rates for psychiatric patients over the general population. Almost all of the excess deaths occurred within two years of discharge, and two-thirds were due to suicides or accidents. Both gender and age affected the elevated death rates: they were higher in women than in men, and they peaked in young adults (ages 21 to 40). These age and gender differences were incorporated into the mortality estimates.

Rheumatoid arthritis more than doubles natural death rates. Pincus and Callahan (1993) published a recent meta-analysis which established a SMR for Rheumatoid Arthritis of 2.26. Excess deaths occurred from infections, pulmonary disease or gastrointestinal disease. There were only small gender differences, and age differences were not reported in a way which made it possible to incorporate them into the estimates.

The literature on asthma was not conclusive. A number of studies indicate that asthma mortality has been elevated, particularly among African American youth (Mitchell 1991, Rao et al 1991, Schenker et al 1993). However, there is a good deal of temporal and geographic instability in asthma deaths (Sly 1994) , and the studies do not converge on a consistent rate of mortality in persons with asthma as an underlying condition. For this paper, it was assumed that the mortality rate for persons with asthma was the same as the general population.

Mortality rates for persons over 21 with Fetal Alcohol Syndrome have not yet been established, since the condition has only been diagnosed during the past two decades. For this paper, the elevated mortality rates for persons who are mentally retarded and living in the community were applied to the FAS population.

DETAILS OF EACH DEFINITION

A: Statutory Conditions Only

This estimate was created using a base of all Washington residents except those in DDD residential facilities, divided into age-by-race/ethnic subgroups.

The disability rates to be applied to those persons came from subsets of the NHIS survey files for three years (1988, 1990 and 1991). These subsets were used to create a subsample of persons who were unable to perform or were limited in performing their major life activity due to mental retardation, cerebral palsy, epilepsy or autism. Than age-by-race rates were determined for the subset, and those rates were multipled by the appropriate age-race subgroups in Washington state's 1990, 1991, 1992 and 1993 populations.

To account for the fact that the NHIS covers only household populations, Institutional and group quarters DDD clients for each year were subtracted from the Washington state regional population file before the rates were applied, and then added back in. This assumes that 100% of those persons met the statutory conditions for DDD eligibility.

For the state as a whole, about 0.8% of the population falls into Group A -- persons who have statutory conditions which have led to limitations in major life activities. However, the "normal curve," which is the theoretical distribution generally applied to IQ tests, gives a theoretical distribution of 2.27% for persons under IQ 70. This suggests that there might be many persons in the population who have IQ below 70 and are quite functional.

During the 1970's, several researchers carried out community studies in which a random sample or a complete census of community residents were given IQ tests (Granat and Granat 1973, 1978; Reschly and Jipson 1976; Birch et al 1970; and Rutter, Tizard and Whitmore 1970). Each researcher tested a slightly different demographic subgroup, and each found a slightly different prevalence rate of persons below 70 IQ, but all rates found were between 2% and 3.5%, just as the predicted distribution from the normal curve would suggest.

In these studies, less than half the persons with IQ between 50 and 70 were known to service providers or in any way "labeled" as mentally retarded. Granat and Granat analyzed the intelligence scores of a random sample of 5,605 Swedish men enlisting in the Armed Forces (which all non-retarded males were

required to do) at age 19. They found that 1.5 percent had an IQ below 70. Many of these had received some special support within the regular school system because of poor school performance; however, most were employed, law-abiding citizens. *"Together with the 0.71 percent who were not enlisted because they were already labeled mentally retarded, the prevalence of 19-year old men in Sweden fulfilling the psychometric criterion for mental retardation was estimated to be 2.21 percent."* (Granat and Granat 1973, 31).

For this paper, it was assumed that the overall national prevalence of mental retardation would be 2.2 percent (including both those with limitations in major life activity and those without). The age and race/ethnicity demographics for retarded persons with major life activity limitations were estimated directly from the NHIS. Those demographic differences were applied to the overall estimate of non-limited persons who had an IQ below 69.

B: Adding Developmental Delay in Persons Under Six

Washington State residents under age six who are not in DDD residential facilities are used as a base, divided into age-by-race/ethnic subgroups. They are multiplied by subgroup prevalence rates from the NHIS for the six to ten year old population. These rates show the percentage of persons limited or prevented from carrying out their major life activity due to any condition EXCEPT mental retardation, cerebral palsy, autism or epilepsy.

No persons over age six are included in this estimate.

C. Adding Developmental Delay in Persons Over Six

Washington State residents over age six who are not in DDD residential facilities are used as a base, divided into age-by-race/ethnic subgroups.

Persons under 21 by subgroup are multiplied by matching subgroup prevalence rates from the NHIS. These rates show the percentage of persons limited or prevented from carrying out their major life activity **mainly due to** any of the conditions shown in Table A-2 below.

The estimated case rate at age 21 is used as a base for persons over 21, but is reduced in five year age groups by mortality rates which are higher than the general population mortality rate.

Table A-2: Definition C Conditions with their NHIS and ICD-9 Codes

Condition	NHIS Codes	ICD-9 Codes
Severe vision impairments or blindness in both eyes	-008 to -027	369_ to 369.4
Hearing impairments in both ears	-05& to -069 -08& to -099	389_ to 389.9
Hyperkinetic syndromes		314.0 to 314.9
Speech defects	-098& to -119, -919	
Specific learning delays	-14& to -114.	315_ to 315.9
Paralysis	-40& to -419, -46& to -469, -64& to -719.	344_ to 344.3
Loss of both legs	-26& to -269	
Loss of both arms	-210	
Loss of organs	-30& to -319	
Brain and spinal cancer		191_ to 192.9, 198.3, 237.5 to 237.6
Immune system disorders		279_ to 277.9
Organic mental disorders		299_ to 294.9, 310_ to 310.9
Central nervous system degenerative diseases and slow viruses		330_ to 337.9, 046_ to 046.9 042_ to 042.9
Congenital abnormalities of the brain and spinal column		740_ to 742.9
Chromosomal abnormalities, not specified		758_ to 759.9.
AIDS and HIV		42.0 to 44.9

Conditions where NHIS has not developed special codes are recorded in the NHIS using the ICD-9 codes

D: Adding Fetal Alcohol Syndrome

The prevalence estimates used to construct Definition D are based upon the research literature on full Fetal Alcohol Syndrome cases. To be diagnosed with FAS, a person must show characteristic facial anomalies, have a history of maternal substance abuse, show very low growth rates during infancy and childhood and exhibit a variety of fine motor and cognitive deficiencies. The frequency of even full FAS cases continues to be debated, because FAS is hard to distinguish at birth, can be confused with other medical problems, is often not noted on medical records, and must be diagnosed by careful history and physical examination rather than a laboratory test (Chevez et al 1991; Bergeson et al 1993; Bloss 1994).

Some consensus exists in the literature on the FAS rate proposed by Abel and Sokol of 1.9 FAS cases per 1000 live births (1987, 1991a). That rate is used in

this paper. It is based upon both prospective and retrospective studies, and hence may overstate incidence. A more conservative estimate of .33 cases per 1000 live births (Abel and Sokol 1991b), depending only upon prospective studies, could have been used. However, that estimate does not include rates for groups which may face elevated risk (such as American Indians), since there are no prospective studies of such groups.

Only a small proportion (5% to 10%) of the children born to alcoholic mothers exhibit full FAS. Persons with some FAS symptoms and a history of maternal alcohol abuse have been labeled "possible Fetal Alcohol Effect" (FAE) or "Prenatal Exposure to Alcohol." Recent clinical and neuroanatomical evidence suggests that many FAE cases have cognitive deficiencies, fine motor impairment, and brain structure anomalies which are as severe as those of persons with full FAS (Olson, Burgess and Streissguth 1992; Coles 1994; Mattson, Jernigan and Riley 1994; Streissguth 1994). However, the prevalence of severe FAE is unknown, and an emerging consensus suggests that alcohol damage exists on a continuum with no clear cutpoints other than FAS. Given the uncertainty about prevalence and diagnosis, it seemed wisest to leave those cases for Definition E, along with non-alcohol related cognitive and physiological problems.

Estimating the number of persons with FAS present in the population for single years begins by creating a population of live births for the previous 100 years. (This population of live births represents persons who have moved to Washington state, as well as those born in Washington, so the base of live births must be inferred from the state's population, rather than generating by summing the babies born here each year). The FAS incidence of .0019 (1.9 FAS births per 1000 births) is then applied to the live births to calculate the number of FAS cases born each year.

Persons with FAS die at a more rapid rate than the general population, so the overall FAS proportion born in each year must be reduced by an FAS-specific, age-specific death rate. The research literature did not define an appropriate death rate, though several authors stated that mortality was elevated in this group. Therefore, in this paper, the rate was assumed to be the same as for mentally retarded persons in the community.

A final reduction: only individuals with FAS who are **not** mentally retarded need to be included in the revised definition, because those who are retarded are included already. According to Streissguth (1994), 58% of FAS cases are retarded. Assuming that all of those qualify for DDD service under Definition A, only 42% of the surviving persons with FAS were added to the pool of prospective clients.

E: Adding All Other Conditions

Here the general principal was to construct the rate of Washington State household residents who had a major activity limitation, and then subtract the other estimates of persons with major activity limitations from that total.

The estimate began with Washington State residents over age six who are not in DDD residential facilities as a base, divided into age-by-race/ethnic subgroups. Persons under 21 by subgroup were multiplied by matching subgroup prevalence rates from the NHIS. These rates show the percentage of persons limited or unable to carry out their major life activity.

After age 21, rates of functional disability were reduced by the increased mortality rates among disabled persons. For this analysis, the reduction was based upon the literature reviewed earlier. 24.6 percent of the disabled population were assigned a rate based upon the mentally ill; 24.6 percent were assigned a mortality rate based upon rheumatoid arthritis, and the remaining 51% were assigned the general population mortality rate.

From the resulting numbers, the persons in definitions A, B, C and D who are functionally disabled were subtracted.

REFERENCES

Aase J M 1994. "Clinical Recognition of FAS: Difficulties of Detection and Diagnosis." *Alcohol Health and Research World: Special Focus: Alcohol-Related Birth Defects* 18(1), 5-9.

Abel E L and R J Sokol 1987. "Incidence of fetal alcohol syndrome and economic impact of FAS-related anomalies." *Drug and Alcohol Dependence* 19, 51-70.

Abel E L and R J Sokol 1991b. "A Revised Estimate of the Economic Impact of Fetal Alcohol Syndrome." Chapter 7 in *Recent Developments in Alcoholism: Volume 9: Children of Alcoholics* ed by M Galenter (New York: Plenum Press).

Abel E L and R J Sokol 1991a. "A Revised Conservative Estimate of the Incidence of FAS and its Economic Impact" *Alcoholism: Clinical and Experimental Research.* 15(3), 514-524.

Allgulander C 1994. "Suicide and Mortality Patterns in Anxiety Neurosis and Depressive Neurosis. *Archives of General Psychiatry 51*, 708-712.

Anderson H R 1992. "Epidemiology of Asthma." *British Journal of Hospital Medicine* 47(2) 99-104.

Barger, L W, W M Vollmer, R W Felt, A S Buist 1988. "Further investigation into the recent increase in asthma death rates: a review of 41 asthma deaths in Oregon in 1982." *Annals of Allergy* (60) January, 33-39.

Becker H C, C L Randall, A L Salo, J L Saulnier, and R T Weathersby 1994. "Animal Research: Charting the Course for FAS." *Alcohol Health and Research World: Special Focus: Alcohol-Related Birth Defects* 18(1), 10-16.

Birch H G, S A Richardson, D Baird, G Horobin and R Illsley 1970. *Mental subnormality in the community: a clinical and epidemiological study"* (Baltimore: Williams and Wilkens).

Black D W, G Warrach, G Winokur 1985a. "Excess mortality among Psychiatric Patients: The Iowa Record-Linkage Study. *Journal of the American Medical Association 253(1),* 5861.

Black D W, G Warrach, G Winokur 1985e. "The Iowa Record-Linkage Study: II. Excess Mortality among patients with organic mental disorders *Archives of General Psychiatry 42*, 78-88.

Black D W, G Warrach, G Winokur 1985b. "The Iowa Record-Linkage Study: I. Suicides and Accidental Deaths Among Psychiatric Patients" *Archives of General Psychiatry 42*, 71-75.

Chavez G F , J F Cordero, J E Becerra 1989. "Leading Major Congenital Malformations Among Minority Groups in the United States, 1981-1986. *Journal of the American Medical Association* 261(2) 205-209.

Coles C 1994. "Critical Periods for Prenatal Exposure: Evidence from Animal and Human Studies." *Alcohol Health and Research World: Special Focus: Alcohol-Related Birth Defects* 18(1), 22-29.

Cordero J F, R L Floyd, M L Martin, M Davis, and K Hymbaugh 1994. "Tracking the Prevalence of FAS" *Alcohol Health and Research World: Special Focus: Alcohol-Related Birth Defects* 18(1), 82-85.

Day N L and G A Richardson 1991. "Prenatal Alcohol Exposure: A Continuum of Effects" *Seminars in Perinatology* (15)4 271-279.

Day, N L and G A Richardson 1994. "Comparative Teratogenicity of Alcohol and Other Drugs" *Alcohol Health and Research World: Special Focus: Alcohol-Related Birth Defects* 18(1), 42-48.

Evans R 3rd 1991. "Epidemiology of asthma in childhood" *Pediatrician* 18(4) 250-256.

Granat K and S Granat 1973. "Below average intelligence and mental retardation" *American Journal of Mental Deficiency* 78, 27-32.

Granat K and S Granat 1978, "Adjustment of intellectually below-average men not identified as mentally retarded." *Scandinavian Journal of Psychology* 19, 41-51.

Jacobson J L and S W Jacobson 1994. "Prenatal Alcohol Exposure and Neurobehavioral Development: Where is the Threshold?" *Alcohol Health and Research World: Special Focus: Alcohol-Related Birth Defects* 18(1), 30-36.

Martin R L , C R Cloninger, S B Guze, P J Clayton 1985. "Mortality in a Follow-up of 500 Psychiatric Outpatients: I. Total Mortality" in *Archives of General Psychiatry 42*, 47-54.

Martin R L , C R Cloninger, S B Guze, P J Clayton 1985. "Mortality in a Follow-up of 500 Psychiatric Outpatients: II. Cause-Specific Mortality" in *Archives of General Psychiatry 42*, 58-66.

Mattson, S N, T L Jernigan and E P Riley 1994. "MRI and Prenatal Alcohol Exposure: Images Provide Insight into FAS." *Alcohol Health and Research World: Special Focus: Alcohol-Related Birth Defects* 18(1), 49-52.

May P A, K J Hymbaugh, J M Aase, and J M Samet 1983. "Epidemiology of Fetal Alcohol Syndrome Among American Indians of the Southwest" *Social Biology* 30(4) 374-387.

May P A 1991. "Fetal Alcohol Effects Among North American Indians" *Alcohol Health and Research World* 15(3) 239-248.

Michael's E K and M L Michael's 1994. "Cellular and Molecular Bases of Alcohol's Teratogenic Effects" in *Alcohol Health and Research World 18(1)* 17-21.

Mitchell E A 1991. "Racial Inequalities in childhood asthma." *Social Science and Medicine* 32(7) 831-836.

Murphy J M, R R Monson, D C Olivier, A M Sobol, A H Leighton 1987. "Affective Disorders and Mortality: a General Population Study" *Archives of General Psychiatry 44*, 473-480.

National Institute on Alcohol Abuse and Alcoholism 1991. "Fetal Alcohol Syndrome". *Alcohol Alert* No. 13, PH 297.

Olson H C, D M Burgess and A P Streissguth 1992. "Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE): A Lifespan View, with Implications for Early Intervention" in *ZERO TO THREE/ National Center for Clinical Infant Programs* 13(1), 24-29.

Paulozzi L J, J J Coleman, A S Buist 1986. "A recent increase in asthma mortality in the Northwestern United States." *Annals of Allergy* 56(5), 392-395.

Pincus T and L E Callahan 1993. "The 'Side Effects' of Rheumatoid Arthritis: Joint Destruction, Disability and Early Mortality" *British Journal of Pheumatology 32 (Suppl 1)*, 28-37.

Rao M, R E Kravath, D Abadco, J Arden and P Steiner 1991. "Childhood asthma mortality: the Brooklyn experience and a brief review." *Journal of the Association of Academic Minority Physicians* 2(3) 127-30.

Reschly D and F Jipson 1976. "Ethnicity, geographic locale, age, sex and urban-rural residence as variables in the prevalence of mild retardation." *American Journal of Mental Deficiency* 81, 154-161.

Rutter M, J Tizard and K Whitmore (Eds) 1970. *Education, health, and behavior.* (London: Longmans).

Schenker M B, E B Gold, R L Lopex, J J Beaumont 1993. "Asthma Mortality in California 1960-1989: Demographic Patterns and Occupational Associations" *American Review of Respiratory Disease* (147), 1454-1460.

Sly R M 1994. "Changing Asthma Mortality." *Annals of Allergy* (73) September, 259-268.

Sokol R J, J Ager, S Martier, S Debanne, C Ernhart, J Kuzma, S I Miller 1986. "Significant Determinants of Susceptibility to Alcohol Teratogencity." *Annals New York Academy of Sciences*

Streissguth A, S Landesman-Dwyer, J C Martin, D W Smith 1980. "Teratogenic Effects of Alcohol in Humans and Laboratory Animals" in *Science* 209(19) 353-361.

Streissguth A P 1994. "A Long-Term Perspective of FAS." *Alcohol Health and Research World: Special Focus: Alcohol-Related Birth Defects* 18(1), 74-81.

Tarjan G, W Wright, R Eyman and C Keeran 1973. "Natural History of Mental Retardation: some aspects of epidemiology." *American Journal of Diseases of Children* 96, 64-70.

Wolfe F, D M Mitchell, J T Sibley, J F Fries, D A Block, C A Williams, P W Spitz, M Haga, S M Kleinheksel, and M A Cathey 1993. "The Mortality of Rheumatoid Arthritis. *Arthritis and Rheumatism 37(4), 481-494.*

Zigler E and R M Hodapp 1986. *Understanding mental retardation.* (New York: Cambridge University Press).